Introduction

People of all ages with disabilities want the same opportunities every American wants: not just to survive, but to thrive. They want to live in their own homes and make decisions about daily activities, so they can go to school, work, church, recreation, and can participate fully in their communities. Historically, people with disabilities have not always been allowed this birthright. Society has often focused on a person's disabilities rather than his or her abilities. But changes in philosophy and law have led to a new approach. People with disabilities are now recognized as being able to live in their own homes and other community settings and to lead satisfying and productive lives when provided the range of services and supports they need to do so.

In the service system for elderly persons, these services and supports are referred to as long-term care. In the disability service system, the terms typically used are long-term services and supports or personal attendant services. All these terms are used interchangeably throughout this Primer.

Medicaid: An Evolving Program with Considerable State Flexibility

The major source of public funding for long-term services and supports provided in home and community settings is the Medicaid program. Medicaid was first enacted in 1965 as a companion program to Medicare.[1] It was designed as a joint Federal-state entitlement providing primarily medical care to low-income Americans.[2] When first enacted, Federal Medicaid funding for meeting the long-term service needs of people with disabilities and chronic conditions was available mainly when the person was placed in an institutional setting (e.g., a nursing home), with few avenues for securing Medicaid dollars to support individuals in their homes and communities. State dollars (and, in some cases, Federal dollars) funded "home care" programs, but only on a limited basis.

In the 35 years since its enactment, Medicaid's "institutional bias" has been progressively reduced through numerous amendments to Federal laws and policy. These amendments have offered new options for states to fund comprehensive home and community long-term services. Beginning in the early 1980s, there has been a steady increase in the options available to states to secure Federal Medicaid dollars to underwrite long-term services and supports in home and other community settings. As a result, states have considerably expanded availability of these services for persons of all ages with physical and mental disabilities. Many states are leading the way in designing innovative and fiscally responsible ways to enable more persons with disabilities to receive necessary services in their communities instead of in institutions.

At one time, only a small portion of Medicaid long-term care spending was directed to home and community services. Today, 28 percent of long-term care spending is for such services, and these outlays are one of the fastest growing components of total Medicaid spending.[3]

Some benefits may be offered through either the state's "regular" Medicaid program or through a home and community-based services (HCBS) waiver program. Moreover, a state may operate several HCBS waiver programs at once, each offering a distinct package of services and supports to a different group of individuals. These choices combine to give states considerable latitude in deciding which services and supports will be offered and in customizing benefit packages to meet the needs of particular groups.

Medicaid home and community services are available to beneficiaries of all ages with many different types of physical and mental disabilities and chronic illnesses. Because of the way Medicaid was originally designed and has been amended over time, distinct programs were developed to provide services to certain categorical populations, most notably women with dependent children. In the long-term care context, covered categories include the "aged, blind, and disabled." These three populations account for the majority of Medicaid long-term care spending on home and community services, primarily through the personal care option, the HCBS waiver program, and the home health benefit. The "aged and disabled" categories taken together include people of all ages who have physical or mental disabilities, including serious mental illness, mental retardation, and other developmental disabilities. The Primer discusses services for all these groups.

Regardless of an individual's age or condition, all persons with disabilities and their families share common goals—to choose how to live their lives and to have some control over their daily activities in the most integrated settings. The recent Supreme Court decision in *Olmstead v. L.C.* affirmed the right of persons with disabilities to do just this.[4] The Court stated that institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Further, the Court noted that confinement in an institution severely diminishes the everyday life activities of individuals—including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.[5] The Court also noted, however, that nothing in the Americans with Disabilities Act (ADA) condones termination of institutional settings for persons unable to handle or benefit from community settings, and that a state's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

The Medicaid program can be an important resource to assist states in meeting the principles set out in the Olmstead decision. States may choose to utilize Medicaid funds to provide appropriate services in a range of settings from institutions to fully integrated community support.[6]

As states work toward the goal of integrating persons with disabilities into the community, they may need to go through a process of fundamentally rethinking how programs serving people with disabilities should be structured and how long-term care resources should be allocated. The Medicaid program as currently structured provides many alternative ways to increase the availability of home and community services and still keep the costs of those services under control.

Subsequent chapters of this Primer stress that states need to consider their own unique needs, resources, and social / political / economic environment as they decide how best to use the Medicaid program to provide home and community services to persons with disabilities. An important context for this decision-making process is the set of demographic factors driving the need for publicly funded assistance by persons with disabilities.[7]

The first such factor is advances in medical technology, which have enabled increasing numbers of people with extensive congenital and acquired disabilities to both survive and live longer lives. The second is that the nation's population is aging and will continue to do so as the baby-boom cohort moves into its 60s and beyond. The population over age 85—numbering 4.0 million in

1998—is the group most likely to need assistance performing activities of daily living, and this is the group that is growing the fastest. By 2020, for example, an estimated 7 million people will be 85 and over.[8]

Finally, most of this assistance is provided by informal caregivers, typically the women in the family. However, high women's labor force participation rates, smaller families, and geographic mobility may make it very difficult for some families to provide such assistance for their members with disabilities.

Purpose, Audience, and Organization of This Primer

Medicaid now offers so many options for providing home and community services that they can be confusing for policymakers, state officials, advocates, and consumers alike. It does not help that the details of these expanded options tend to be buried in the minutiae of Medicaid legislative and regulatory provisions. To add to the confusion, the extensive flexibility states have to combine these options has resulted in 50 different state Medicaid programs. Even people who have spent years working in Medicaid do not always understand its many provisions.

This Primer is designed to encourage use of the Medicaid program in a manner that minimizes reliance on institutions and maximizes community integration in a cost-effective manner. Its intended audience is policymakers and others who wish to understand how Medicaid can be used—and is being used—to expand access to a broad range of home and community services and supports, and to promote consumer choice and control. In addition to comprehensive explanations of program features states can implement to achieve these goals, the Primer presents examples of state programs that have taken advantage of Medicaid's flexibility to expand home and community services for people of all ages with disabilities.

The service options reviewed in subsequent chapters span the full range of Medicaid choices. They address program modifications states can implement as a state plan option (without special waiver of Federal law), as well as those for which Federal waiver approval must be obtained. Options that do not require waivers offer especially important potential for expanding community services and supports.

The design of this Primer grew out of a series of discussions among Federal officials, state policymakers, service providers, and advocates regarding how to make the document as useful as possible. Each chapter provides an annotated bibliography, with full information on how to obtain each publication.

- *Chapter One* provides a brief overview of the legislative and regulatory history of Medicaid's coverage of home and community services and information on current home and community expenditures.

The next four chapters lay out and discuss the basic elements involved in Medicaid's financial and functional eligibility criteria and service coverage alternatives.

- *Chapter Two* provides an explanation of Medicaid's financial eligibility criteria, one of the most complicated areas of Medicaid law. It first discusses the general eligibility criteria all Medicaid beneficiaries must meet. It then focuses on the financial eligibility provisions most important for receiving services in home and community settings. It also discusses the options states can select to ensure that people with disabilities will be able to support themselves in home and community settings.

- *Chapter Three* focuses on Medicaid provisions related to health and functional criteria used to determine service eligibility for home health services, the personal care option, and the waiver program. It presents examples of states with service criteria that support a social model of long-term services and supports rather than a medical model. And it discusses ways in which states can design service criteria to ensure that they appropriately and adequately measure the need for services and supports among heterogeneous populations.

The Olmstead Decision[9]

The Olmstead case was brought by two Georgia women whose disabilities include mental retardation and mental illness. At the time the suit was filed, both plaintiffs lived in State-run institutions, despite the fact that their treatment professionals had determined that they could be appropriately served in a community setting. The plaintiffs asserted that continued institutionalization was a violation of their right under the ADA to live in the most integrated setting appropriate.

The Supreme Court ruled that "Unjustified isolation . . . is properly regarded as discrimination based on disability."[10] It observed that (a) "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," and (b) "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

Under the Court's decision, States are required to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when: (a) the State's treatment professionals reasonably determine that such placement is appropriate; (b) the affected persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others who are receiving State-supported disability services. The Court cautioned however, that nothing in the ADA condones termination of institutional settings for persons unable to handle or benefit from community settings. Moreover, the State's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

Under the ADA, States are obliged to "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity." The Supreme Court indicated that the test as to whether a modification entails "fundamental alteration" of a program takes into account three factors: the cost of providing services to the individual in the most integrated setting appropriate; the resources available to the State; and how the provision of services affects the ability of the State to meet the needs of others with disabilities. (See Appendix II for the complete text of HCFA's guidance on the *Olmstead* decision.)

- *Chapter Four* presents the major service options states have to provide home and community services to people with disabilities and discusses the factors states need to consider when choosing among the various options.

- *Chapter Five* provides an in-depth discussion illustrating different coverage alternatives in the context of two specific services: case management and assisted living for elderly persons.

The last four chapters focus on key policy goals in the provision of home and community services and supports.

- *Chapter Six* discusses factors states need to consider when developing initiatives to *transition institutional residents back to home and community settings.* It also presents ways in which Medicaid can be used to facilitate this transition.

- *Chapter Seven* discusses options under Medicaid to *increase consumer choice and control* of home and community services.

- *Chapter Eight* discusses ways in which Medicaid can support *informal caregiving and family support* through various optional services.

- *Chapter Nine* addresses system design issues and discusses how Medicaid can be used to *create comprehensive, cost-effective long-term care systems.*

The Primer concludes with a series of Appendices that provide additional information about the Medicaid program.

This Primer has been prepared by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), with consultation from the Health Care Financing Administration (HCFA) in the United States Department of Health and Human Services (HHS). Designed to serve as a reference guide, it is written in easily understood language, but with sufficient annotation of source material to fulfill its technical support role. Some issues remain unresolved, because particular provisions of Medicaid regulations and state interpretations thereof are being challenged in the courts. Major unresolved issues are discussed where relevant.

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This Primer describes the many options states have to use the Medicaid program to fund long-term care services and supports. It is up to state policymakers working with the disability and aging communities to identify the unique needs and goals of the state, and then use the information given in the following chapters (a) to choose the options best suited to a particular state and (b) to decide how the options chosen can be best used in that state.

Endnotes

1. P.L. 89-97, Title XIX of the Social Security Act.

2. The Federal government provides matching funds on an open-ended basis for every dollar a state chooses to spend on Medicaid services.

3. Burwell, B. (April, 25, 2000). Memorandum: Medicaid long-term care expenditures in FY 1999. Cambridge: The MEDSTAT Group.

4. *Olmstead v. L. C.*, 119 S.Ct. 2176 (1999).

5. Ibid.

6. Health Care Financing Administration. (February 1, 2000). Fact Sheet: Assuring access to community living for the disabled. (Available from www.hcfa.gov/facts.)

7. Because the focus of the Primer is on long-term care services and supports, the Primer uses the term persons with disabilities to refer primarily to that group of persons with disabilities who need long-term care services in general, and home and community services in particular.

8. U.S. Census Bureau (www.census.gov).

9. Information in this text box is available from the following website: www.hcfa.gov/medicaid/smd1140a.htm, which contains additional information regarding the Olmstead decision.

10. The Olmstead decision interpreted Title II of the ADA and its implementing regulations, which oblige states to administer their services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” (28 CFR 35.130(d)).